

Questionnaire to be filled in by patient and physician

Dear patient, dear parent,
Please fill in this questionnaire as far as possible. Please mark the fields which you cannot answer yourself and ask your physician to complete them during your visit today.

Name: _____ **Today's date:** _____

Date of birth: _____

Date of last news from patient: _____

No news during the past year

Date of last visit at your centre: _____

Current status: alive deceased → please complete questionnaire for "Deceased Patient"
 lost to follow-up

The patient was discharged after complete recovery

Current weight: _____

1. Have there been changes in diagnosis?

no yes, the following:

No PID after all.

New PID diagnosis: _____

Affected gene: _____ No mutation found No genetic analysis performed

Date of genetic diagnosis: _____ unknown

Sequencing method

Gene sequencing Whole exome/genome sequencing unknown

2. Are you currently being treated with immunoglobulin replacement? yes no

If yes,

Current brand name: _____

Route of application: subcutaneous intravenous intramuscular

Place of application? home therapy in-patient clinic out-patient clinic

Dose: _____ (_____ mg/kg) **How often?** _____

Side effects: yes no unknown

If yes, type of side effects:

- | | | |
|--|---|--|
| <input type="checkbox"/> Anaphylaxis | <input type="checkbox"/> aseptic meningitis | <input type="checkbox"/> Fever |
| <input type="checkbox"/> Headache | <input type="checkbox"/> Local side effects (rash, swelling...) | |
| <input type="checkbox"/> Renal failure | <input type="checkbox"/> Venous thrombosis | <input type="checkbox"/> Arterial thrombosis |

Other, specify: _____

3. Have you received a stem cell transplant (HSCT) in the past year? yes no

If yes, date of transplantation _____

Donor: MSD (Matched sibling donor) MUD (Matched unrelated donor)
 MMUD (Mismatched unrelated donor) Haplo-identical (parent) donor
 other related donor unknown

Source of stem cells: bone marrow cord blood peripheral blood unknown

4. Have you been treated with gene therapy in the past year? yes no

If yes, date of therapy: _____

Thank you for taking the time for the ESID Registry!

